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Pediatric to Adult Care:

A Family Resource for Navigating PKD Care Transition

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Introduction to Healthcare Transition

Transitioning from **pediatric** to adult-focused healthcare is a normal, gradual, and essential process that typically starts between the ages of 12–14. For teens and young adults with **autosomal recessive polycystic kidney disease (ARPKD)** and **autosomal dominant polycystic kidney disease (ADPKD)**, there are special considerations and extra steps needed to support a successful transition. This guide aims to help young people and their parents or caregivers take control of their health while ensuring uninterrupted, high-quality care.

Why This Transition Guide Matters

Transitioning from pediatric to adult care can be challenging for young people with PKD and their families. This guide is designed to support young people with developing the skills to manage their health, maintain access to knowledgeable **providers**, and receive ongoing support for their medical, emotional, and social needs.

Without a structured plan, challenges may arise, including:

- **Gaps in Care:** Missed appointments or unclear responsibilities can disrupt care.
- **Reluctance to Leave Trusted Providers:** Strong bonds with pediatric teams can make change difficult.
- **Trouble Finding a Provider with Sufficient Experience:** Many adult doctors are unfamiliar with ARPKD or pediatric ADPKD.
- **Over-Involved Parents or Caregivers:** This may unintentionally delay a youth's independence.
- **Limited Self-Management Skills:** Adolescents and young adults may feel unprepared to take responsibility for their health.
- **Low Confidence in Talking to Healthcare Professionals:** Without exposure and experience, adolescents may feel nervous or unsure about how to communicate with healthcare professionals.

Transition is the process of preparing a patient to move from pediatric to adult care. It includes learning about their health, building self-care skills, understanding medications, and planning for adult providers.

Transfer is the stage within this process when the patient's care officially moves from the pediatric team to the adult care team, with medical records and treatment responsibility handed over.

How to Use This Guide

You don't need to read this guide all at once—use the parts that are helpful to you when you need them. Here are some tips to consider:

- **Go Step by Step:** Follow the timeline and tips by age or stage to know what to focus on.
- **Use it in Conversations:** Bring it to doctor's appointments to ask questions and make a plan.
- **Check Off Skills:** Use the checklists in this guide to track progress and build independence.
- **Share It with Your Team:** Give copies to doctors, nurses, social workers, and anyone helping with the transition.
- **Come Back to It:** Keep the guide handy—it can be useful throughout the whole transition process.
- **Refer to the Glossary:** If you see a word in **teal bold**, you can find its definition in **"Section VII: Glossary and References"** at the end of this guide to help you understand what it means.

Who Should Use This Guide

This guide is for anyone involved in helping a young person with PKD move from pediatric to adult health care. It's meant to support a smooth, informed, and successful transition.

- **Youth with PKD:** Will learn how to take more control of their health and prepare for adult care.
- **Parents or Caregivers:** Will understand what to expect and how to support their child during this transition.
- **Pediatric Healthcare Teams:** Will help start and guide the transition process early. This includes pediatric nephrologists, social workers, educators, and patient advocates who support children and families as they prepare to move to adult care.
- **Adult Healthcare Teams:** Will understand the background and needs of young patients coming from pediatric care.

Section I: Transition Timeline and Milestones

Each transition plan should be customized to a young person's needs, preferences, and current level of social and emotional development. With that in mind, here's a list of things for parents or caregivers to consider at each age and stage as you prepare.

Ages 12–14: Early Foundations

This section is for parents or caregivers, helping guide early transition conversations and building foundational knowledge with their child about PKD and self-care.

Begin Transition Conversations: Start the transition conversation early with the healthcare team and your child, emphasizing that this isn't an immediate change in doctors.

Discuss the Pediatric Center's Transition Policy: Get introduced to the transition process, ensure you understand the clinic's approach, and find out the age when patients typically transfer to adult care.

Involve the Young Person with PKD in Appointment Preparation: A few days before appointments, sit down with your child to help them write down any notes, questions, important updates, or concerns. Teach them that being prepared is the best way to make sure they get the help they need at each visit.

Utilize Available Educational Resources: Involve social workers and other educators to get age-appropriate handouts and resources.

Patient Perspective

"My doctors and mom made sure I understood my condition well enough to explain it even if I was alone. They also taught me the importance of taking my medications every day."

– *Individual living with ARPKD*

Key Topics to Begin Discussing and Learning About with Your Child

- **Medical Basics:** Develop a foundational understanding of ARPKD/ADPKD.
- **Assess the Young Person's Understanding of PKD:** Check in with your child to see if they understand PKD and want to learn more. If not, try again later. When they're ready, ask them to look up facts or tips about PKD to help you understand what interests or challenges them most. To find resources and information on PKD, please refer to **"Section VII: Glossary and References."**
- **Condition Overview:** What is ARPKD/ADPKD and how it impacts health.
- **Medications:** Habits like taking medication at the same time each day or pairing them with a routine are important because they help people with PKD stay healthy and on track with their treatment plan.

- **Symptoms and Monitoring:** How to identify symptoms that require attention.
- **Lifestyle and Diet:** Begin discussing appropriate lifestyle changes and diet.
- **Dialysis Considerations:** Talk with your child and review dialysis basics and why they need it. Review the difference between **hemodialysis (HD)** and **peritoneal dialysis (PD)** and why they might receive one versus the other.

Early Transition Planning Checklist:

Monitor Your Child's Progress (For parents and caregivers)

- ☑ Build a basic understanding of PKD (ARPKD/ADPKD) and how it affects health
- ☑ Review medications, daily routines, and why consistency matters
- ☑ Learn to recognize symptoms that require medical attention
- ☑ Begin discussions about lifestyle, diet, and long-term care needs (including dialysis basics, when appropriate)
- ☑ Begin conversations with the healthcare team about transitioning to adult care early (no immediate change in doctors)
- ☑ Review the pediatric clinic's transition policy and typical transfer age
- ☑ Involve your child in preparing for appointments (questions, concerns, updates)
- ☑ Use educational and support resources, including social workers and educators

Patient Perspective

"The two ways I've learned the most about PKD are through my nephrologist and the PKD Foundation website. Having the initial talk with my nephrologist was helpful in the sense that he knew everything I was going through that was new to me, helping me both learn and process this disease. The information found on the PKD Foundation website added to what I learned since then. The nurse and dietician are also easily accessible through the hospital app if I have questions between my appointments."

– *Individual living with ADPKD*

Ages 14–18: Developing Independence

This section is for parents or caregivers and their adolescent child, supporting the development of independence and planning for the transition to adult care.

Increase Independence: Start encouraging independence and **self-management** of your adolescent's health.

Encourage Conversation with Providers: Support your adolescent child by encouraging them to ask questions, share information, and take the lead in **communication** during their healthcare visits. Allow them to spend some time alone with their doctor after the appointment for more one-on-one practice and for anything they'd like to discuss in private.

It's common and standard practice for your child's doctor to request to speak with them privately during visits once they enter adolescence.

Teach Medication Self-Management: Teach your child about pillbox management, refills, and the importance of taking medications as prescribed. Some important information they should know about their medications includes:

- What each medication is for
- If medications can cause any side effects
- If food/drink or other medications should be avoided while taking their medications
- Specific instructions for taking medications, such as timing (time of day) and whether to take them with food or on an empty stomach

Dialysis Considerations: Teach your child how to begin managing care and monitoring symptoms.

- Daily care of your adolescent's dialysis access type (such as a **fistula** or **PD catheter**) is an important skill they can begin participating in at this age. They should understand how to help prevent infection with good hand hygiene, proper cleaning of the access site, and use of protective equipment such as masks and gloves.

Patient Perspective

"I am very involved in managing my PKD. My parents are here to support me, but I have to make conscious decisions for myself. The main thing that I've had to get used to handling is my diet, specifically watching my sodium intake and drinking a lot of water. I continue to become more responsible for what foods I eat. I've noticed that among my friends, I am the only person who examines food packages before I eat. There is a sense of discipline that I need when eating food with people so as not to get lost in the communal aspect and consume things in amounts that are harmful to my kidneys."

– *Individual living with ADPKD*

- Checking daily weight and blood pressure
    - Weight may be required to take at certain times during the day or before and/or after dialysis.
    - Keep in mind that blood pressure should not be taken on the arm with the dialysis access site.
- Tracking fluid intake may be especially important if they are on hemodialysis.
- Encourage them to track and share any symptoms and concerns they have directly with their doctor and dialysis staff.

Introduce Shared Decision-Making: An approach that encourages patients and their healthcare team to work side by side in choosing the treatment plan that's right for them. This allows the individual to consider the recommended treatment options, benefits, and risks while also considering their own values, goals, and preferences.

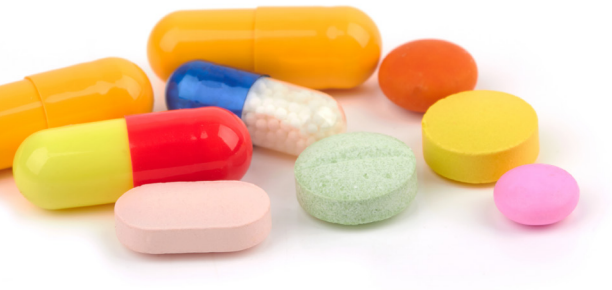
Start Planning Transition Logistics

- **Timing of Transfer:** Address when to transfer care, considering geographic location, stability, and education/work plans.
- **Adult Doctors:** Begin identifying adult primary care (the main doctor you see for your health needs) and specialist doctors (doctors who specialize in a specific area of medicine).
    - Talk with your pediatric doctors to see if they have any recommendations on who to see. Clinics with PKD experts can also be found at pkdcure.org/find-care.
- **Insurance and Social Worker Support:** Make sure appropriate insurance coverage and necessary support systems are in place.
    - Check to see which doctors are in- or out-of-network with your insurance.
    - Your insurance may require **referrals** from your primary doctor to see new specialist doctors.
- **Consider Overlapping Care:** Develop a staged transition plan. For example, at the age of 18, start with transferring to the adult primary care doctor first, followed by one specialist, then another after each transfer is complete and successful.
    - Each pediatric hospital system or clinic has different practices and policies. Depending on the severity of the disease or if there are complex needs that require a longer transition process, some may be able to continue seeing patients past the age of 18.
- **Dialysis Considerations:** If receiving dialysis during transfer to adult care, make sure to talk with both your pediatric and adult nephrologists about where dialysis will be done after the transfer to adult care is complete. Contact the adult dialysis center to arrange a tour and meet the dialysis staff, including the dialysis nurses and medical assistants, social worker, and administrator.

- Here are some important topics to discuss with the dialysis center's social worker and administrator before transferring care:
  - Make sure they have all necessary medical records ahead of the first appointment
  - Check if insurance is in- or out-of-network and if they can help coordinate insurance coverage
  - Ask how to schedule appointments
  - Find out who to contact for questions and/or concerns during and after hours
  - Learn about arranging transportation to and from appointments as needed

TIP:

As a parent or caregiver, establish a time each day to talk with your child about medications, treatments, symptoms, and any questions in a calm, quiet environment.



Developing Independence Checklist:

Monitor Your Progress

(With support from a parent or caregiver)

- ☑ Practice taking the lead during medical appointments and asking questions
- ☑ Spend part of each visit alone with the healthcare provider
- ☑ Learn medication self-management (purpose, timing, refills, and side effects)
- ☑ Track and communicate symptoms and concerns directly to your doctors
- ☑ Participate in shared decision-making about treatment options
- ☑ Begin planning transition logistics (timing, adult providers, insurance coverage)
- ☑ Explore a gradual transition plan, including overlapping pediatric and adult care
- ☑ Begin participating in dialysis care and symptom monitoring (if applicable)

Ages 18–21: Taking the Lead

This section is for young adults and their parents or caregivers, helping guide the transfer from pediatric to adult care.

Execute the Transition

- **Transfer to Adult Primary Care:** First, consider transferring to an adult primary care doctor, if applicable, followed by specialists.
- **Coordinate Specialist Transfer:** Ensure coordination for nephrology (kidney) and other specialties as necessary.
- **Transfer all Medical Records:** Make sure all important medical records are shared and that a "warm handoff" takes place—meaning the pediatric and adult care teams talk directly—so everyone understands your needs and no important information is missed.
    - Talk with the pediatric care team about sending medical records ahead of time and ask how long the transfer process usually takes, so your new healthcare team has these records in time for your first appointment.
- **Connect with Adult Doctors Early:** Ensure you've met with your new adult doctors before concluding pediatric care.
- **Set a Final Pediatric Visit**: Try to have one last visit with the pediatric care team before moving to adult care. During this visit, talk about how the transition is going and what might be needed in the future. If unable to go in person, a video (**telehealth**) appointment might be possible.
    - Ask if there may be any new or different tests the adult care provider might recommend that you haven't already done, such as **total kidney volume (TKV)** imaging or intracranial aneurysm (ICA) screening.
- **Dialysis Considerations:** If you transfer care to an adult nephrologist while receiving dialysis, you'll want to discuss transplant eligibility and care options and see if the clinic or hospital system has a transplant team to coordinate care with your adult nephrologist.

Patient Perspective

"Looking forward to transitioning to adult PKD care in the near future, I am excited to be able to see treatments that aren't out even today. The progress when it comes to combatting the disease has come an immense distance and I am very blessed to be in a position where I can look forward to being an adult who can take medicine that is currently available and also the progress to be."

– *Individual living with ADPKD*

- **Legal Changes:** At age 18, the young adult reaches legal adulthood, and parents no longer have automatic access to health information.
    - Consider discussing and setting up a Durable Healthcare Power of Attorney to ensure continued parental involvement in healthcare decisions if the young adult and parent would like a continued level of parental involvement. For more details, please refer to **"Section IV: Legal, Logistical, and Life Considerations."**
    - Most healthcare facilities allow for additional individuals to be listed on a HIPAA (Health Insurance Portability and Accountability Act) form. This would be a good place for a young adult to list if there's a parent or caregiver they want to have access to their medical records.
    - An adult patient (18 years or older) can give access to a parent or caregiver through their patient portal (e.g. MyChart) and take away access at any time. The care team can help the young adult navigate this process during their office visit.

Taking the Lead Checklist:

Monitor Your Progress (For young adults)

- ☑ Transfer to adult primary care, followed by specialty care as needed
- ☑ Coordinate transfer of nephrology and other specialty providers
- ☑ Ensure all medical records are sent and a "warm handoff" occurs between care teams
- ☑ Meet adult providers before pediatric care ends
- ☑ Schedule a final visit with the pediatric care team to review next steps
- ☑ Review whether new or additional testing may be recommended in adult care
- ☑ Understand legal changes at age 18 regarding medical decision-making
- ☑ Complete HIPAA forms and consider a healthcare power of attorney, if desired

Transition Time and Key Considerations

Remember, each individual and family is unique, and institutions and clinical practices may have different approaches to the timing and structure of the transition process. These varying needs can affect how long the transition may take. Most pediatric doctors can continue caring for patients beyond the age of 21 (during the transition process), if the young adult and parents or caregivers agree it's necessary to maintain consistent care until a safe and effective transition can be made.

Learning Assessment: PKD can affect a young person's ability to learn and can include delays in growth and development. Some recommendations for parents or caregivers and their healthcare team may include:

- Provide age-appropriate resources
- Explain medical language in ways that are appropriate for the young person's age and development
- Use correct anatomical terms rather than nicknames to reduce confusion during medical discussions
- Ask a member of the healthcare team for creative ways a young person can engage in their care

Maintaining a Consistent Approach: It can be challenging to find time in a busy schedule to actively involve a young person in their care. Important factors for parents and caregivers and their healthcare team to consider include:

- According to research on pediatric decision-making (Bosch et al., 2024) and the ***KDIGO 2025 Clinical Practice Guideline for the Evaluation, Management, and Treatment of Autosomal Dominant Polycystic Kidney Disease (ADPKD)***, involving young people in decisions about their care can help them:
  - Stay engaged with their treatment plan and take an active role in managing their health.
  - Get involved in their care and participate in decision-making, reflecting that children and adolescents want to be part of managing their own care.
- Beginning in the earliest phase of transition (ages 12–14), taking the time to consistently include your child in discussions and decisions about their care helps ensure they're prepared to transition to adult care and manage their condition independently by the time they turn 18.
- Keep in mind that it will take time, but with patience and consistency, your child will slowly build the knowledge, confidence, and the desire to manage their care more independently each day.

Skill-Building for Independence

Begin discussions with your child at ages 12–14 to help them gradually build health knowledge, confidence, and independence.

Medication Management: Keeping track of medications is a big step in managing health. Ask the doctor if they recommend a medication log and reminder program or phone app. These apps can:

- Keep a list of current, discontinued, and as-needed medications.
    - Utilize online resources available in your hospital system (e.g. MyChart) that allow you to keep track of medications.
- Tell you what each medication is used for.
- Keep track of daily medication schedules.
- Send reminders to take medications.
- Help log side effects or missed doses.

Communication Skills: Learning to talk about your health is another important step in becoming independent. These skills can help young people:

- Explain their condition in their own words.
- Share important information with teachers, coaches, or friends.
- Communicate with their doctor about questions and concerns.
- Clearly describe symptoms (such as pain or headache) or side effects (from a medication or treatment).
- Practice saying medication names out loud.
- Empower them to advocate for their health and wellbeing by asking for support.
- Stay informed and up to date about the disease process, clinical recommendations, and treatment options.

Patient Perspective

"In high school, my parents taught me more about my medications—how they work, why I need them, and how to fill my own pill boxes. Learning to organize my pills myself was a big step in becoming more independent with my health."

– *Individual living with ARPKD*

Tracking Tools and Patient Portals

Home Blood Pressure Tracking: Writing down blood pressure readings (or measurements), medication doses, and timing can help build daily habits and notice changes to discuss during doctor's visits.

- Speak with your doctor for specific instructions on how to monitor blood pressure, what numbers to aim for, and how to log readings and any symptoms. Questions you might ask include:
    - Ask your doctor about symptoms to look for with high blood pressure and when to call the office to report concerns.
    - Ask your doctor if you can track symptoms on your smart phone or smart watch and what apps they recommend using.

Keeping Track of Symptoms: Noting how the young person feels each day and keeping track of symptoms—like pain, swelling, blood pressure changes, or changes in urine—can help identify patterns over time. Writing them down or using an app makes it easier to remember details for appointments, helps the care team make better decisions, and ensures nothing important gets missed. Regular tracking can also show whether treatments are working or if adjustments are needed.

TIP:

Learning how to talk with the healthcare team by phone is an important step in helping your child become more independent. You can start by practicing simple calls together, such as scheduling or confirming an appointment. Once your child feels more comfortable, try making calls that involve questions about symptoms or medications Before the call, help your child write down what they want to say and keep their medication list or any questions handy. Remind them that it's normal to feel nervous—healthcare teams are used to supporting young people as they learn and are there to help both of you.

Tracking Labs and Imaging: Ensure understanding of lab work and imaging, and how doctors use them. Common labs and imaging tests that monitor kidney and liver function and overall health include:

- **Blood tests:**
    - **Basic metabolic panel (BMP):** Checks how the kidneys are working and monitors electrolytes.
    - **Complete blood count (CBC):** Checks for infection, anemia (low iron), or inflammation.
    - **Complete metabolic panel (CMP):** Checks how the kidneys and liver are working.
    - **Creatinine:** A blood test (obtained from a BMP, CMP, or RFP) used to check how the kidneys are filtering waste.
    - **Estimated glomerular filtration rate (eGFR):** A test (obtained from a BMP, CMP, or RFP) used to check how the kidneys are filtering waste and stages of chronic kidney disease (CKD). See the **CKD Stages** table to review the stages of CKD.
        - Pediatric and adult nephrologists calculate eGFR differently, which may lead to a different eGFR level from the adult nephrologist. It may appear higher or lower than in the past. Ask the pediatric and adult nephrologists to explain the formula they're using and how eGFR may change after transferring to adult care. This is important as monitoring frequency and treatment options may depend on the eGFR level.

- **Gamma-glutamyl transpeptidase (GGT):** Checks how the liver is working.
- **Hemoglobin A1c (HbA1c):** Checks the average blood sugar level over the past several months and is used to diagnose or monitor prediabetes or diabetes.
- **Renal (kidney) function panel (RFP):** Checks how the kidneys are working, monitors electrolytes, and includes more specific measurements to monitor kidney function.
- **Lipid panel:** Checks cholesterol and triglyceride levels.
- **Liver function test (LFT):** Checks how the liver is working.

CKD Stages

Stage	Description	eGFR (mL/min/1.73 m^2)	Kidney function (%)
1	Possible kidney damage (e.g., due to cysts) with normal kidney function	90 or above	90-100%
2	Kidney damage with mild loss of kidney function	60-89	60-89%
3a	Mild to moderate loss of kidney function	45-59	45-59%
3b	Moderate to severe loss of kidney function	30-44	30-44%
4	Severe loss of kidney function	15-29	15-29%
5	Kidney failure	Less than 15	Less than 15%

- **Urine tests:**
  - **Urinalysis:** Checks for signs of kidney problems, infections, or other health issues by looking for protein, red blood cells, or white blood cells in the urine.
  - **Urine protein/creatinine ratio:** Checks for protein in the urine (including albumin, a protein that may appear when the kidneys are not working properly, and creatinine, a natural waste product used to help measure levels) to look for kidney problems, infections, or other health issues.
  - **Urine albumin/creatinine ratio:** Checks how much albumin (a type of protein that can leak into urine when the kidneys are damaged) is in the urine. It also uses creatinine (a natural waste product) to help measure and compare levels. This test is more sensitive for detecting early stages of kidney disease.
- **Ultrasound (US):** The most common and least invasive imaging test that can look at the size and number of cysts on the kidneys and liver.
- **Magnetic resonance imaging (MRI):** Can show the kidneys in greater detail and measure total kidney volume (TKV) to help assess how advanced the kidney disease is and how it might progress over time.
  - TKV is a measurement used mostly in adults with ADPKD to monitor and help determine the disease progression and if the patient may be eligible for treatment.
- **Check the patient portal (such as MyChart)** to view test results before or after appointments. Look for changes since the last tests and write down questions to discuss with the doctor. During the next visit, ask the doctor about lab and imaging results and what these results mean.

Always talk with your primary care doctor and specialists about which lab tests they prefer to use and what each test is for. For example, some doctors may prefer to use an RFP versus a BMP.

Patient Perspective

"One of the best things I did was let my mom see my test results and talk to my doctors with me. She could hear everything that was going on, and it really helped to have another person who knew exactly what I was dealing with."

– *Individual living with ARPKD*

TIP:

If lab or imaging tests are ordered, let all your healthcare providers know. They may be able to combine tests or add additional tests so everything can be done at once, helping avoid extra trips and needle sticks. When scheduling, ask the lab and imaging departments to set up the appointments close together on the same day. Young adults and parents or caregivers can work together to understand this process, helping the young adult learn how coordination of care works.

Patient Portals: This is a secure website or app used to view health records, message the healthcare team, and schedule appointments.

- In many healthcare systems, young people can begin using limited portal access around ages 12–13, usually to see appointments and basic test results, while parents still control most of the account.
- Between ages 14–17, teens often have expanded access and can message providers and manage more of their care, though some information may be private based on state law and hospital policy.
- At age 18, the young adult has full, independent access and control of their patient portal. In their patient portal, they can:
    - See upcoming appointments
    - Schedule future appointments
    - Read lab and test results
    - Review medications
    - Message the doctor or nurse
    - Check past visit notes
    - Attend telehealth visits with your doctor
- If your doctor uses a system like MyChart, you can download the app or use the website to log in. You can ask your care team how to create and access your patient portal and what information you should pay attention to, such as kidney function numbers, blood pressure, or new lab or imaging results.

Patient Perspective

"MyChart is one of the most helpful tools I have—it lets me message my doctor anytime, check past results, see when my appointments are, and more. It makes managing my health so much easier."

– *Individual living with ARPKD*

Practicing Independence in Care

Practice Makes Confidence: When young adults turn 18, they'll take the lead in managing their own healthcare. Parents or caregivers can support this by gradually giving them more independence during clinic visits.

Here are some simple ways to build those skills:

- **Encourage Independent Transportation:** If the young adult has a driver's license, driving to the appointment can help build confidence and independence.
- **Have the Young Adult Call and Schedule Appointments:** This helps them practice talking to the healthcare team and answering any questions they might have over the phone, like insurance or copays.
- **Support Solo Visits:** If a parent or caregiver is present, they can wait outside while the young adult meets with the doctor alone. This allows for practice in communicating directly with the healthcare team.

- **Practice Preparing Questions:** Writing down a few questions or concerns before the appointment helps build comfort in talking with the doctor and encourages active participation in care.

After each appointment, it can be helpful to reflect on the experience by considering the following questions:

- What was it like to meet with the doctor alone?
- Were all questions asked, and were the answers clear?
- Was anything confusing or hard to talk about?
- Did the visit help increase understanding of the care plan?

Reproductive Health and Family Planning

As young people grow into adulthood, it's important for them to learn about their **reproductive health** and how to make informed choices about their future. Parents or caregivers can help support these conversations while helping the young adult understand how their kidney condition may affect their health, relationships, and family planning decisions. Practice the following skills together:

- **Shared Decision-Making:** Encourage involvement in care decisions
- **Private Conversations with Doctors:** Normalize private health discussions, including sensitive topics like mental health and relationships

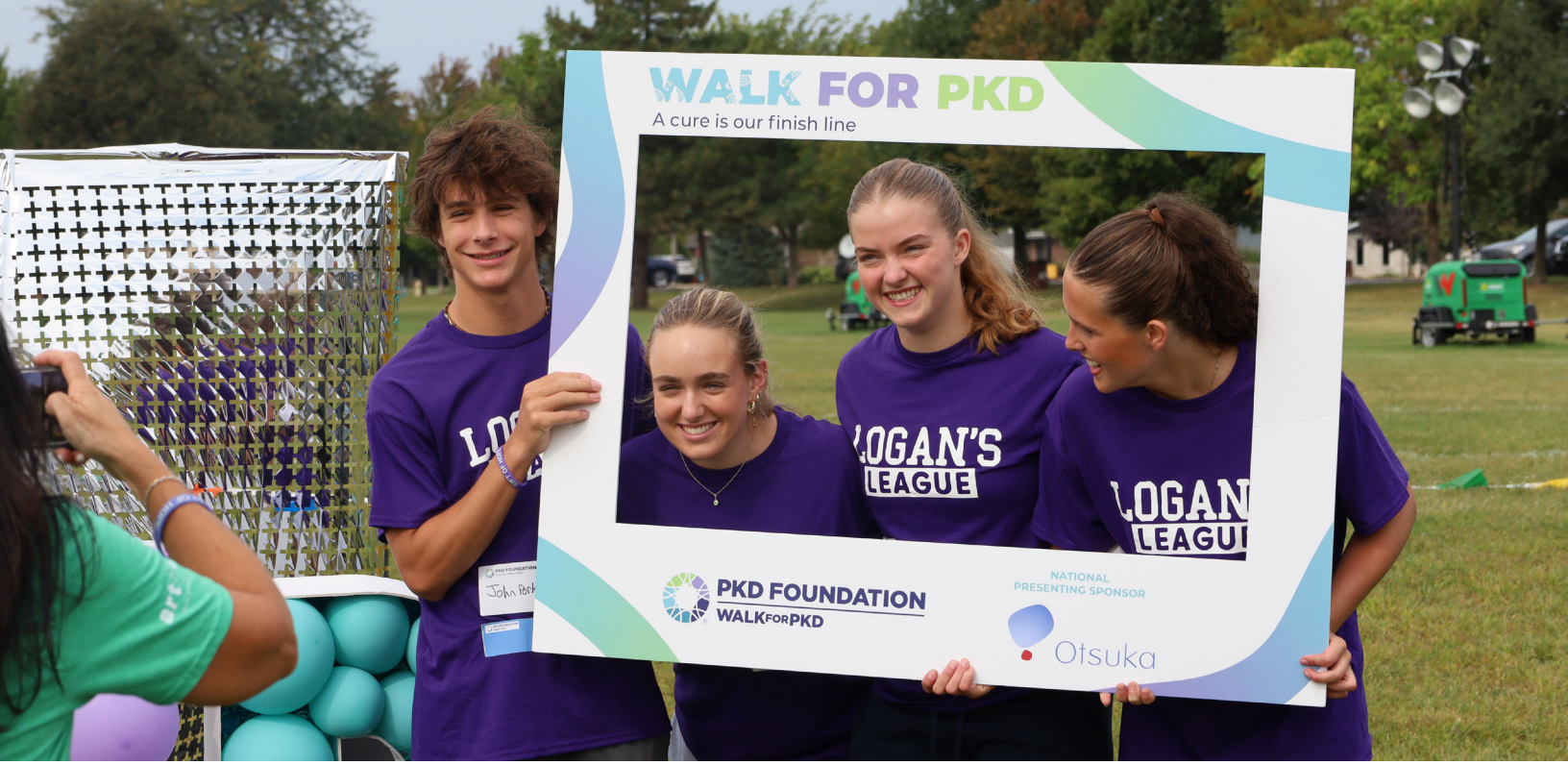
Understanding the Genetic Side

Some kidney conditions, like ARPKD and ADPKD, can be passed down to children. Young adults should learn about the genetic part of their condition so they can think about this if they want to plan for a family in the future. Talking to a genetic counselor can help them understand their options when they're ready.

Ask whether your pediatric care team offers genetic counseling services. If not, request recommendations for genetic counseling options in your area or ask whether the future adult provider has access to a genetic counselor.

Talking with Doctors

It's normal and healthy for young people to have private conversations with their healthcare team. These talks might include questions about dating, sex, birth control, how their condition or medications could affect fertility or pregnancy, and other special considerations. Creating a safe space for these conversations helps young people feel more confident and respected.



Special Considerations for Transplant Patients

Young adults who've had a kidney transplant need to be extra careful about infections. Some medications can weaken the immune system, so using protection and talking about safe sexual health practices is very important. Certain medicines may also affect the ability to get pregnant or make it unsafe during pregnancy; planning ahead with a doctor is key.

Special Considerations for Dialysis Patients

For patients on dialysis, planning for reproductive health and family planning requires extra support. Dialysis can affect fertility and pregnancy, so it's important to discuss timing, risks, and options with the healthcare team. Patients with ARPKD may have additional medical considerations, and individualized guidance from a nephrologist or maternal-fetal medicine specialist is recommended.

Coordinating care with the dialysis team, social worker, and insurance providers can help young people manage both health and daily life while planning for pregnancy or family goals. Practical issues such as transportation to dialysis sessions, insurance coverage, and Medicare eligibility should also be considered. Many young people rely on family, friends, or community programs for transportation to treatments. Understanding how insurance or Medicare covers dialysis, medications, and related care can help avoid unexpected costs and ensure continuous treatment.

Encouraging Independent Decision-Making

Young adults should be included in decisions about their reproductive health. This helps build confidence and supports healthy habits as they move into adult care. Parents or caregivers and doctors should encourage young people to ask questions, express their values, and make informed choices.

Shared Care and Coordinated Support

The shared care model allows patients to receive routine care from their primary care provider while also seeing a specialist, such as a nephrologist, for more complex medical needs. In this approach, both providers communicate and work together to coordinate treatment plans, share important medical information, and ensure care is aligned. This team-based model helps prevent gaps in care and supports smoother transitions as a patient's needs change.

This model is particularly helpful when access to a **PKD Foundation Center of Excellence (COE) program care center**, is limited. The PKD Foundation's **COE program** is a nationwide network of clinics dedicated to delivering high-quality, specialized PKD care. It outlines standards for PKD care, increases understanding of PKD through research, educates clinicians, and empowers the PKD community.

The shared care model can also support the transition from pediatric to adult care. A key part of this process is a **warm handoff**, where the pediatric and adult teams communicate directly, share medical records, and collaborate to ensure the new care team fully understands the patient's history, needs, and goals. This intentional coordination helps prevent gaps in care and reduces the stress of changing providers, while allowing young adults to build confidence as they adjust to a new healthcare team.

The COE program includes four types of care center designations, divided into adult and pediatric care. **Centers of Excellence** and **Partner Clinics** focus on adult PKD care, while **Pediatric Centers of Excellence** and **Pediatric Clinics** focus on pediatric PKD care.

For more information on the PKD Foundation Centers of Excellence, please refer to **"Section VII: Glossary and References."**

Finding an Adult Nephrologist

Why Can't I See My Pediatric Nephrologist as an Adult?

As young adults grow older, their healthcare needs change. Pediatric nephrologists are doctors who specialize in treating children and adolescents with kidney problems. But once a young adult turns 18, it's important to prepare for the switch to an adult nephrologist.

Adult nephrologists are trained to handle the health needs of young adults, helping them manage chronic conditions and take on more responsibility for their health. Pediatric doctors don't specialize in adult health issues, so this transition is an important step for continued care.

Key Things to Think About When Moving from a Pediatric to an Adult Nephrologist

- **Insurance and Referrals:** When switching to an adult nephrologist, check if the new doctor is "in-network" with the young adult's insurance. This will help make sure the transition is affordable. Some insurance plans might also require a referral from the current pediatric nephrologist.
- **Access to Care:** Think about any possible challenges to getting care. Does the doctor's office offer interpreter services (in-person or virtual)? Do they provide telehealth (virtual) visits as an option? Is there a social worker on site to help with transportation or financial support? These types of resources can make it easier to access and receive the care needed.
- **Coordinated Care Services:** Look for a clinic or doctor's office where different types of care are all in one place. For example, having access to a transplant team, dialysis services, lab tests, dietitians, or social workers all in one place can help make managing care simpler. A team that works together can make the transition smoother and more efficient.
- **Knowledge of PKD:** Not all adult nephrologists know about conditions like ARPKD or ADPKD. It's important to find a doctor who is familiar with these conditions or is willing to work with the young adult's current care team to ensure the best possible treatment.
    - The PKD Foundation's Centers of Excellence program lists doctors and clinics, or care centers, that specialize in PKD and provide high-quality care.
    - For more information on ADPKD care recommendations, refer to the *ADPKD Patient Handbook and Understanding the KDIGO 2025 ADPKD Clinical Guideline: A Plain Language Guide*, in **"Section VII: Glossary and References."**
    - For more information on ARPKD, refer to the *ARPKD Patient Handbook* listed in **"Section VII: Glossary and References."**

TIP:

If a provider your child sees in pediatric care is not available in adult care, talk with the pediatric nephrologist or primary care physician about this early. Let them know which specialists your child currently sees who may not exist in adult care. Together, you can plan how to get connected to the right adult providers before the transition.

Finding the right adult nephrologist takes time, but it's an important step in making sure young adults continue to get the care they need.

Establishing a Comprehensive Adult Care Team

Establish a team that includes a nephrologist (kidney doctor), geneticist or genetic counselor, hepatologist (liver doctor), therapist, and social worker to ensure comprehensive care and support.

Specialists You May See as Part of Your Care

- **Genetic counselor:** A licensed healthcare professional who explains how PKD can run in families and what it might mean for the young adult and their relatives
- **Geneticist:** A doctor who helps people understand inherited conditions like PKD, what it means for health, and options for genetic testing
- **Gynecologist/Obstetrician/Adolescent medicine:** Doctors who support reproductive health and pregnancy planning
- **Hepatologist:** A doctor who treats liver-related health issues
- **Neurologist:** A doctor who treats conditions affecting the brain, spinal cord, or nervous system
- **Neurosurgeon:** A doctor who performs surgeries for conditions or injuries of the brain, spinal cord, or nerves
- **Pain management specialist:** A doctor who helps treat short-term or long-term pain
- **Psychiatrist:** A doctor who helps with emotional or behavioral challenges and can prescribe medication, if needed
- **Psychologist:** A doctor or licensed healthcare professional who supports mental and emotional health, and coping and behavior skills
- **Radiologist/Interventional radiologist:** Doctors who read imaging tests and may perform procedures using imaging guidance
- **Renal nutritionist/Dietitian:** A licensed healthcare professional who helps create healthy eating plans for kidney health and overall wellness
- **Research coordinator:** A trained professional who manages research studies, helping patients participate safely and collecting important information
- **Social worker:** A licensed professional who helps families access resources, insurance, school support, and other assistance
- **Surgeon/Transplant surgeon:** A doctor who performs surgeries, including kidney or liver transplants and dialysis access procedures
- **Urologist:** A doctor who treats conditions of the urinary system, including the bladder and kidneys

TIP:

Pediatric and adult care teams may differ. For example, child life specialists (CLS) are often part of pediatric teams to support patients during treatments, but they typically aren't part of adult care teams. Knowing these differences can help you prepare for the transition.

If one of the pediatric team members doesn't exist in adult care:

- **Ask the pediatric team** for ideas, tools, or resources to help keep that support going in a new way (such as different specialists, community resources, or increased self-management) when moving to adult care. The following resources offer helpful information and recommendations on transitioning to adult care and are also listed in **"Section VII: Glossary and References."**
  - **Got Transition®**
    - www.gottransition.org
  - **American Society of Transplantation**
    - Pediatric Transition Portal: www.myast.org/pediatric-transition-portal

Patient-centered care means that patients and doctors work together to make decisions and create a care plan to fit the patient's unique needs. As patients move from pediatric to adult care, they may face new challenges and responsibilities. By involving them in decisions and tailoring the care to their specific situation, it makes the transition smoother and supports their independence, health, and well-being. It also ensures that both the patient and their care team are on the same page about the best path forward.

Patient Perspective

"Having a psychologist/psychiatrist early on can make a big difference when you're facing multiple health issues at a young age."

– *Individual living with ARPKD*

Living Arrangements and Healthcare Access

Think about whether the young adult will be living at home, going to college, or moving to a new place. Consider any challenges, like getting around, finding a place to live, and getting healthcare.

Since many young adults have temporary living situations, some pediatric doctors may let them stay in pediatric care for a little longer. It's important to ask the pediatric doctor how long they can continue providing care to help reduce the number of changes in their health care.

Healthcare Access:

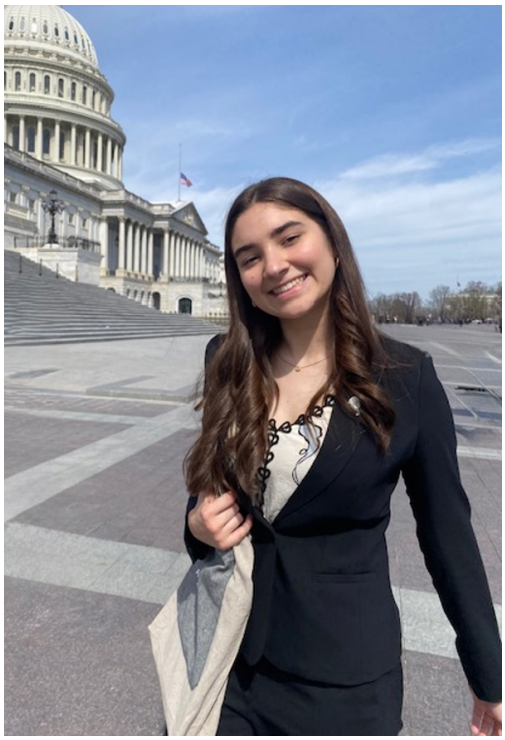
- **For those who've moved away from home:**
  - Find a local lab or imaging center where your doctor can order routine tests, especially if done frequently.
  - Ask your healthcare team if labs or imaging may be needed between visits and how often (for example, every two weeks or every two months).
  - Make sure the clinic knows about your PKD diagnosis and can access your medical records if needed.
- **For those attending college:**
  - Check if your college has an on-campus health clinic or a clinic nearby.
  - With a doctor's note, your college can offer accommodations, such as excused absences for medical appointments or when you're not feeling well.
  - Keep your healthcare team informed and make sure your medical records are accessible if needed.
- **For those with dialysis:**
  - Plan transportation to dialysis sessions, using family, friends, or community programs.
  - Understand your insurance or Medicare/Medicaid coverage for dialysis, medications, and related care.
  - Work with your social worker or dialysis team to ensure smooth access to care and support.

Emergency Care Preparations:

- Identify the nearest hospital or emergency facility to your new home or college that's equipped to manage kidney-related emergencies and other illnesses such as infections or dehydration.
- Identify one or more emergency contacts, like parents or caregivers or close friends. If you live far from your primary emergency contact, make sure to also have someone nearby who you can trust to help in an emergency.
- Keep emergency contact information readily available (such as on a phone, card in your wallet, or student ID).

Pharmacy Coordination:

- Identify a local pharmacy near you that can handle regular medication refills and transfer your prescriptions.
- Set up mail-order or delivery services for ongoing medication access.
- Many mail-order pharmacies provide only a three-month supply, so check with your pharmacy and schedule follow-up visits with your provider before running out of medication.



Telehealth Continuity:

- Check if your nephrologist at home offers telehealth appointments and can continue managing your care while you're at school or away.
- Ask if the provider prefers virtual visits or in-person visits.
- Schedule virtual follow-up visits as needed to stay on track with your care.

Scheduling Visits During School/Holiday Breaks:

- Proactively plan nephrology and specialist appointments to align with school/holiday breaks (e.g. winter, spring, summer breaks) or when going back home.
- Plan to get lab work or imaging done before your appointments so results are ready. If you use a shared care model, you can do these tests at a local clinic and have follow-up visits with your main specialist.

Understanding and Using Health Insurance

As young adults transition into adult care, it's important to learn how health insurance works. Knowing how to use insurance helps get the care needed and avoid surprise bills.

Key Terms to Know:

- **Insurance policy number:** A unique number that belongs to the insured person. It helps doctors and hospitals find their health insurance information.
- **Insurance card:** Shows healthcare coverage information and should be brought to all medical and pharmacy visits.
- **Copay:** A set fee paid at the time of service or the visit, such as $20 for a doctor's visit or $10 for a prescription.
- **Premium:** The amount paid each month to keep insurance coverage active.
- **Deductible:** The amount paid each year before insurance starts covering more of the cost of healthcare services.
- **In-network doctors:** Doctors and clinics that work with the insurance plan. The cost is less when using providers that are in-network.
- **Out-of-network doctors:** Doctors and clinics that do not work with the insurance plan and are not covered or more expensive. Always check before scheduling an appointment to see if the doctor/clinic is out-of-network and what the cost of services will be.
- **CPT codes:** Numbers provided by the doctor's office that tell insurance companies what kind of medical service or treatment was provided, like a check-up or a blood test.

Using and Managing Insurance:

- **Review Insurance Coverage:** It's important to make sure the insurance plan covers adult care, especially when moving from a child-specific plan like the Children's Health Insurance Program (CHIP). Talk with the healthcare team about the best time to transition from a parent or guardian's plan, which is usually by age 26, and decide what type of insurance will be needed going forward. If the young person is also on Medicaid, be sure to review coverage details and options with the healthcare team and social worker to make sure all care needs are covered.
- **Coordinate Benefits:** Make sure there are no gaps in coverage when switching from pediatric to adult care. If coverage changes, plan ahead to ensure the new health insurance plan is active during the transition and when beginning to see the adult providers.

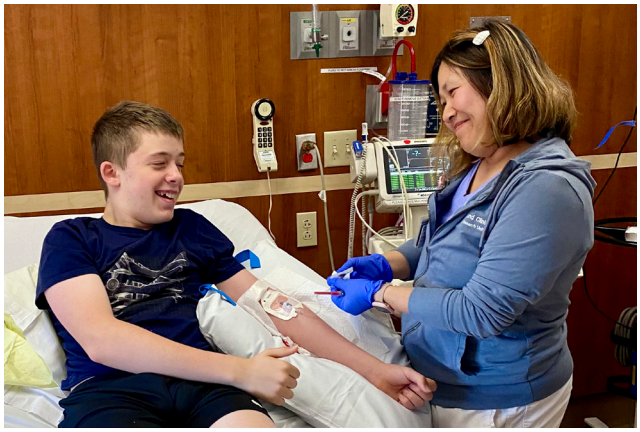
- **Know What's Covered:** Take time to understand the insurance plan by reading the documents or calling the phone number on the insurance card to see what services, specialists, and medications are included. If there are questions about specific procedures, contact the doctor's office for the CPT codes to determine whether insurance will cover them. Many plans also have online portals to check coverage and find additional information.
- **Find In-Network Doctors:** Use the insurance company's website or app to locate the doctors and clinics covered under the plan. Take time to review and compare available plans to make sure they include the adult kidney and specialist providers.
- **Ask Questions:** Not sure what something costs or if it's covered? Ask the doctor's office or call the insurance company.
- **Keep Track of Records:** Save medical bills, Explanation of Benefits (EOBs), and insurance letters.
- **Renew the Insurance Plan:** Re-enroll each year, especially if on a family or individual plan—this usually happens during open enrollment in the fall.
- **Respond Promptly to All Communications from Insurance Companies and Other Health Services:** Respond promptly to all messages from the insurance company and other health services to avoid any lapse in coverage. If there is a move or change of address, be sure to notify both the healthcare team and insurance company to continue receiving important mail about care and insurance coverage.

Durable Healthcare Power of Attorney and HIPAA Access

As young people get older, they'll have more control over their health care decisions. It's important for them to understand their legal rights, and how to give trusted adults, like parents or guardians, permission to help if needed.

What Is a Durable Healthcare Power of Attorney?

A **Durable Healthcare Power of Attorney (HCPOA)** is a legal document that lets an individual choose someone (like a parent or guardian) to make medical decisions on their behalf if they become unable to make decisions. This person is called the **healthcare agent**.



- It only goes into effect if a person is unable to make decisions (for example, if unconscious or very sick).
- They must be ages 18 or older to fill out this form.
- The patient or young adult can change or cancel it at any time.

How to Set Up a HCPOA:

- Ask the doctor, hospital, or social worker for a Durable Healthcare POA form.
- The individual or young adult creating the HCPOA will need to sign it, and depending on the state, witnesses or a notary might be needed.
- A copy of the signed HCPOA should be kept by the patient or young adult and shared with their healthcare agent, medical doctors, and lawyer (if applicable).

How Can Parents Access Medical Records?

Once a young adult turns 18 years of age, their health information is private—even from their parents—unless given permission, which is a personal choice.

If a young adult would like to share medical information with a parent, caregiver, or loved one, ask the clinic or hospital for a **HIPAA release form**. This form allows the 18-year-old to choose what information to share and with whom. It only allows someone to see the young adult's records or talk to their doctors. It does **not** give someone the power to make decisions on their behalf.

How Is This Different from a Durable Healthcare Power of Attorney?

- A **HIPAA release** gives someone permission to access another's health information.
- A **Durable Healthcare POA** gives someone the legal right to make medical decisions for another if they're unable to.

Both can be helpful tools for staying safe and supported when moving into adult care. It's a good idea to talk with parents or caregivers and the healthcare team to decide the level of involvement that works best for the young adult.

Patient Perspective

"Turning 18 and stepping into adulthood was definitely scary for me, but I made sure my mom could access my medical records and talk to my doctors, if needed, by signing the HIPPA form. It really helped knowing that she could support me when things felt overwhelming."

– *Individual living with ARPKD*

Section V: Preparing for the First Adult Appointment

What to Bring and How to Prepare

Send Medical Records: Ensure that medical records are transferred to the adult care doctor before the appointment, and bring any physical copies listed below to your first visit with the adult physician.

What to Bring to The First Appointment with an Adult Physician

(Use this as an interactive tool)

- ☑ Parking instructions
- ☑ Directions to the doctor's office
- ☑ All medications
- ☑ Symptom tracking journal (if available)
- ☑ Medical records (e.g. imaging, labs, progress notes); try to send these ahead of time and also bring physical copies
- ☑ Insurance card(s)
- ☑ Driver's license
- ☑ Primary care doctor's name and contact information
- ☑ Name and contact information for other specialists seen
- ☑ Emergency contact information
- ☑ List of questions
- ☑ Notepad and pen or mobile notes app
- ☑ Signed Durable Healthcare Power of Attorney form, if applicable

Clarify After-Hours Contact: Ensure the young adult understands how to contact the healthcare team after hours and who to call if new symptoms or concerns arise.

Involve Caregivers: Parents or guardians may be invited to the first visit for support but should allow the young adult to take the lead in their care.

Prepare Questions: Young adults transitioning to adult care should come prepared with a list of questions. Here are some examples to help get started.

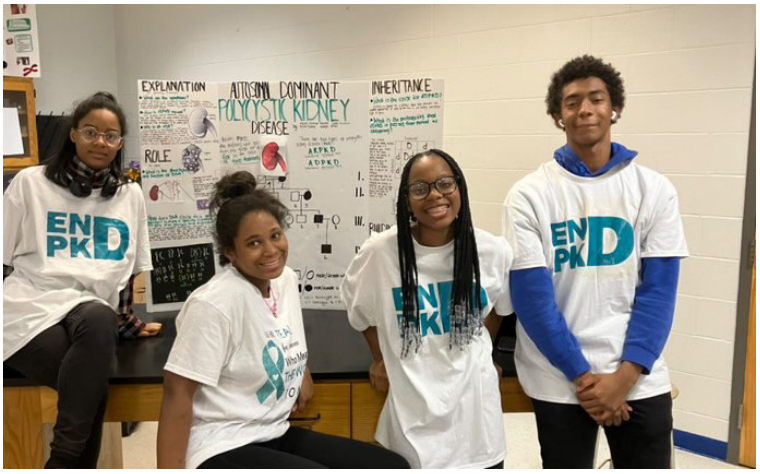
TIP:

If you want to learn more about clinical trials and what research studies are available, visit the PKD Foundation's "Clinical Trials" webpage (listed in the glossary). It explains current clinical trials in a clear and helpful way and can help you understand your options.

- **Treatment Plan and Follow-Up Visits**
  - How will you check my kidney function, and how often will it be monitored?
  - Is my blood pressure in a healthy range, how frequently should it be measured, and what is the correct way to take my blood pressure?
  - Do you have all the medical records and information you need from me?
  - Will I need any new lab or imaging tests?
  - When should I schedule my next appointment?
  - What's the best way to contact you for questions, symptoms, or concerns?
  - Are there any current treatment options available?
  - Do you think I'm likely to need treatment in the future? If so, when?
- **Nutrition and Lifestyle Questions**
  - Should I change my diet or lifestyle?
  - How can I best manage pain or discomfort related to PKD?
  - What are potential complications and symptoms I should look for?
  - Can PKD affect my ability to work, exercise, or do other daily activities? How can I manage this?
  - Do I have any activity restrictions?
- **Medication Questions (For new medications when they are prescribed)**
  - Do you have a medication information pamphlet?
  - What does this medication do and what are the important things to know?
  - What are the possible side effects?
  - Is it dangerous to take this medication with any specific foods, beverages, or other medications (including over-the-counter medications)?
  - Will any other condition I have been aggravated or made worse by this medication?
  - Are there alternatives to this drug (generic brand, other medication, different treatment)?
  - What should I do if I forget to take my medication at the right time?
- **Clinical Trials Questions (If you're interested in learning more)**
  - What are clinical trials and why are they important?
  - Are you aware of any current clinical trials for this disease that I may be eligible for and benefit from?
  - How do I sign up for clinical trials?

Section VI: Psychosocial Support and Community Resources

Supporting Emotional and Social Health



Psychosocial support is a vital component of the pediatric-to-adult healthcare transition because it addresses the emotional, social, and developmental challenges that often arise during this period of change (NEJM Catalyst, n.d.). Here's why it's especially important:

- **Helps with Emotions:** Switching to adult care can feel scary, stressful, or confusing. Having support during this time can help young people feel calmer and more confident about the changes ahead.
- **Builds Independence:** Support helps young people learn how to take care (and be in control) of their health by making appointments, taking medicine on time, and talking with doctors on their own.
- **Improves Communication:** Learning to communicate, ask questions, and talk clearly with new doctors and nurses is an important part of the transition. Support can help build these skills.
- **Supports Mental Health:** Living with a long-term illness can lead to feelings of sadness, stress, or anxiety. Support during the transition can help catch these problems early and connect young people with the help they need.
- **Helps Families Adjust:** Parents or caregivers often manage most of their child's care. Transition support helps them step back gradually while giving their child more responsibility and independence.
- **Keeps Care on Track:** Young people who feel ready for the transfer of care are more likely to continue going to their doctor appointments and following their treatment plans.

Every young person's transition journey is unique, and it's normal to feel both excited and uncertain about the changes ahead. With the right support, from parents or caregivers, family, and healthcare teams, young people can build confidence, independence, and the skills to take charge of their health. Remember, asking for help and using available resources is a sign of strength, and small steps taken consistently can make the move to adult care smoother and more successful.

PKD Foundation Resources

ADPKD Registry

https://pkdcure.org/research/the-adpkd-registry

If you have ADPKD, your experience could be the key to helping future generations. It's the nation's first dedicated ADPKD Registry and one of the first patient registries of any kind to integrate patient-provided health records. By sharing your disease and experience and connecting your electronic health records, your data can help power the path to a cure.

ADPKD Patient Handbook

https://go.pkdcure.org/TransitionGuideADPKDHandbook

The ***ADPKD Patient Handbook*** provides clear, easy-to-understand information about **autosomal dominant polycystic kidney disease (ADPKD)**. It's designed for people living with ADPKD, those who may be at risk because a parent has the disease, and family members or friends who want to learn more. (This handbook is not intended for those affected by autosomal recessive polycystic kidney disease, ARPKD.)

ARPKD Patient Handbook

https://go.pkdcure.org/TransitionGuideARPKDHandbook

The purpose of this handbook is to provide information about **autosomal recessive polycystic kidney disease (ARPKD)** and **congenital hepatic fibrosis (CHF)**. It will be useful to children and families who've been diagnosed with ARPKD/CHF, as well as family members, caregivers, and health professionals. It's not intended for those with ADPKD.

Clinical Trials and ACT Alerts

https://pkdcure.org/research/clinical-trials

The PKD Foundation's "Clinical Trials" webpage provides easy-to-understand information about current PKD research studies. Patients can also sign up for ARPKD or ADPKD Accelerating Clinical Trials (ACT) Alert emails, which notify you about studies that may be available in your area. Only studies approved by an Institutional Review Board (IRB) are included to ensure they meet ethical and research standards.

Understanding the KDIGO 2025 ADPKD Clinical Guideline: A Plain Language Guide

https://go.pkdcure.org/TransitionGuideKGDIGOGuide

This guide was created by the PKD Foundation to help patients, care partners, and families understand the latest medical recommendations for ADPKD. It summarizes the key points from the *KDIGO 2025 Clinical Practice Guideline* in plain language and supports shared decision-making with your healthcare team.

PKD Centers of Excellence Program

https://pkdcure.org/research/centers-of-excellence

The PKD Centers of Excellence Program is a collection of designated care centers nationwide to ensure better care, increase understanding of PKD through research, educate clinicians, and empower the community.

PKD Foundation Communities

https://pkdcure.org/get-connected/community

Communities are groups of PKD patients, family members, and loved ones who want to learn, connect, and take action with others. There are communities based on where you live, as well as two virtual communities: PKD Parents and PKD Thrive (see below for additional details.)

PKD Connect Peer Mentors

https://pkdcure.org/get-connected/peermentors

PKD Connect Peer Mentors provide resources, guidance, motivation, and emotional support to people impacted by PKD.

PKD HOPE Line

https://pkdcure.org/get-connected/hope-line

Connect with our support team by dialing **844-PKD-HOPE (844-753-4673)**. Our team is available Monday through Friday from 8 a.m. – 5 p.m. (CT) to answer your questions and direct you to the resources you need.

PKD Parents Community

https://pkdcure.org/get-connected/community/parents

The PKD Parents Community offers support, compassion, guidance, and can help connect families with experts and other local PKD families who understand what they're experiencing.

PKD Thrive Community

https://pkdcure.org/for-parents/pkd-thrive

The PKD Thrive Community was launched in 2022 to bring together young adults with PKD. PKD Thrive offers support, compassion, and a safe place to connect and interact with others who understand where you are on your PKD journey. Email volunteers@pkdcure.org for more information and to get involved.

Other Resources

American Society of Transplantation

www.myast.org/pediatric-transition-portal

A free online resource that helps teens and young adults with chronic conditions move from pediatric care to adult care. It includes tools and checklists to build skills, track readiness, and support young people as they learn to manage their own health.

Got Transition®

hwww.gottransition.org

A free, national online resource that helps teens, young adults, families, and healthcare teams prepare for the change from child-focused health care to adult health care. It offers tools, checklists, quizzes, and guides to build skills, plan for adult care, and make the transition smoother for youth and their parents or caregivers.

Section VII: Glossary and References

Glossary of Terms

Autosomal dominant polycystic kidney disease (ADPKD)

ADPKD is one of the most common genetic conditions caused by a change in a single gene. It leads to many fluid-filled cysts forming and growing in the kidneys. Over time, this damage often causes the kidneys to stop working properly.

Autosomal recessive polycystic kidney disease (ARPKD)

ARPKD is a rare, genetic disease that usually shows up in childhood. It also causes many cysts to grow in the kidneys. The severity can vary, but the cysts often lead to loss of kidney function.

Care Center

A clinic or hospital within the PKD Foundation's Centers of Excellence program that provides specialized care for people with PKD.

Centers of Excellence (COE) program

A nationwide network of special clinics and hospitals recognized by the PKD Foundation for providing expert care for people with PKD.

Child life specialist (CLS)

A trained professional who helps children understand medical procedures and cope with being in the hospital. They use play, education, and emotional support to help kids feel more comfortable. CLSs are usually not part of the adult healthcare team.

Communication

The ability to talk clearly with doctors, ask questions, and understand information about your health.

Fistula

A type of vascular access to get blood from the patient to the hemodialysis machine during hemodialysis (HD).

Hemodialysis (HD)

A type of dialysis that removes extra fluid, electrolytes, and waste from the blood using a dialysis machine.

Pediatric

Medical care and treatment provided to children and adolescents.

Peritoneal dialysis (PD)

A type of dialysis that removes extra fluid, electrolytes, and waste using the lining of the abdominal cavity.

Peritoneal dialysis (PD) catheter

A flexible plastic tube that allows dialysis fluid to enter the abdominal cavity, dwell inside for a while, and then drain back out again. PD catheter placement is considered a minor operation, and complications are rare.

Physician

Another word for doctor. Someone who is trained to take care of your health and treat illnesses.

Provider

A person or place that gives you medical care. This can be a doctor, nurse, specialist, hospital, or clinic.

Referral

A letter or approval from your current doctor that allows you to see a specialist, like an adult nephrologist.

Reproductive health

Health topics related to puberty, periods, birth control, pregnancy, and sexual health.

Self-management

The ability to take charge of your own healthcare, like remembering to take medicine, making appointments, and asking questions during doctor visits.

Telehealth

A way to see your doctor through video/phone call using a phone, tablet, or computer instead of going to the office in person.

Total kidney volume (TKV)

A measurement of the size of your kidneys obtained by radiological testing.

Transfer

The process when the patient's care officially moves from the pediatric team to the adult care team.

Transition

The process of moving from pediatric (child) healthcare to adult healthcare. It involves preparing the patient to take more responsibility for their health.

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PKD Foundation Disclaimer

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Patients should always consult a qualified healthcare professional for the best care and treatment for their specific case.

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